Recommendations arising from the National Audit of Care at the End of Life 2024

The National Audit of Care at the End of Life 2024 focuses on practice in acute and community hospitals in England, Wales and Jersey. This document outlines the NACEL 2024 recommendations, supplementary information, linked national standards and supporting data.

Content:

National Audit of Care
at the End of Life 2024
Auditing last days of life in hospitals

HQIP
Healthcare Quality
Improvement Partnership

Recommendations 1: Oversight of hospital improvement plans

Recommendation:

Integrated care boards, health boards and commissioners should ensure system level oversight of provider quality improvement plans relating to end of life care. For example:

- Having named clinical and executive leadership with responsibility for care at the end of life in both provider and commissioner organisations. This may include a system collaborative quality improvement group with oversight assurance of delivery
- Signing up to NACEL Data and Improvement Tool to understand provider performance of the 10 NACEL Key Indicators
- Requesting receipt of the annual NACEL report and recommendations from the provider within 4 weeks of publication
- Requesting sight of the end of life care quality improvement plan and subsequent activity updates from providers at least once a year

National recommendation responsibility:

Integrated care boards, health boards and commissioners

Guidance available

- Palliative and end of life care: Statutory guidance for integrated care boards (ICBs). NHS England. Document first published: 20 July 2022
- Quality statement for palliative and end of life care for Wales. Welsh Government. First published: 7 October 2022

NACEL 2024 evidence

- **81%** of hospital/sites report having implemented quality improvement plans relating to end of life care in the past three years
- **12%** of hospital/sites report that they are currently planning quality improvement plans relating to end of life care
- **7%** do not have a quality improvement plan relating to end of life care

Of the hospital/sites that implemented quality improvement plans relating to end of life care in the past three years,
- **74**% had shared these with the ICB/Health Board,
- **26**% had not shared these with the ICB/Health Board

Example NACEL results to share with the ICBs, health boards and commissioners include:
- **83%** of patients were expected to die during the final hospital admission
- **84%** of patients expected to die during the final admission had an individualised plan of care addressing their needs at the end of life
- There was documented evidence that the likelihood of dying was discussed with the patient in **79%** of cases, and discussed with those important to the dying person in **93%** of cases (or where not possible, a reason was recorded)
- **12%** of bereaved respondents strongly disagreed or disagreed that the dying person received sufficient pain relief during the final hospital admission
- Communication with those important to the dying person about hydration options was documented in **62%** of clinical cases notes (or where not possible, a reason was recorded)

- **46%** of bereaved people who required spiritual, religious or cultural support agreed that staff tried to meet their needs.
- The care and support provided to the dying person was rated as excellent or good by **75%** of bereaved respondents, whilst **73%** of bereaved respondents rated the care and support given to themselves and others as excellent or good

Recommendation 2: Access to specialist palliative care services

Recommendation:

Integrated care boards, health boards and commissioners should ensure that services provide specialist palliative medical and nursing cover face-to-face, 8 hours a day, 7 days a week and a 24-hour, 7 days a week, telephone advice service. For example:

- Understanding existing provision of specialist palliative care in hospital including a gap analysis against NICE Standard QS13
- Working collaboratively with providers to develop and implement time-bound action plans to mitigate gaps in access to palliative care services
- Taking account of the population need to match service provision to ensure high quality end of life care, including specialist palliative care where indicated, is delivered for all dying patients
- Publishing strategic plans about system-wide access to specialist palliative care

Supplementary information:

a) All staff should have access to telephone advice and support from specialist palliative care services (nurse and/or doctor), 24 hours a day, seven days a week
b) All staff should have access to face to face advice and support from specialist palliative care services (nurse and/or doctor), 8 hours a day, seven days a week

National recommendation responsibility:

Integrated care boards, health boards and commissioners

Guidance available

- End of life care for adults. NICE Quality standard [QS13]. Quality statement 4: Out-of-hours care. Published: 28 November 2011
- End of life care for adults: service delivery. NICE guideline [NG142]. 1.12 Providing out-of-hours care. Published: 16 October 2019
- Palliative and end of life care: Statutory guidance for integrated care boards (ICBs). NHS England. Document first published: 20 July 2022

NACEL 2024 evidence

- **97%** of hospital/sites have access to a specialist palliative care service

Of hospitals/sites with access to specialist palliative care:

- **61%** of hospitals/sites have face-to-face specialist palliative care availability, 8hr a day, 7 days a week (Nurse and/or Doctor)

- **90%** of hospital/sites have 24/7 telephone specialist palliative care availability (Nurse and/or Doctor)

Recommendation 3: Improve personalised care and support planning

Recommendation:

Integrated care boards, health boards and commissioners should lead on collaborative improvement initiatives to increase the number of personalised care and support planning conversations, including advance care planning conversations, offered to patients. Further ensuring planning is shared across the system, including with the inpatient teams. For example:

- Actively seeking and learning from examples of governance and quality improvement initiatives to address unwarranted variation, including reviewing the NACEL Good Practice Compendium
- Monitoring the implementation of improvement work, considering its sustainability along with reviewing the trends in the metrics published by NACEL

National recommendation responsibility:

Integrated care boards, health boards and commissioners

Guidance available

- End of life care for adults. NICE Quality standard [QS13]. Quality statement 2: Advance care planning. Published: 28 November 2011
- End of life care for adults. NICE Quality standard [QS13]. Quality statement 3: Coordinated care. Published: 28 November 2011
- End of life care for adults: service delivery. NICE guideline [NG142]. 1.6 Advance care planning. Published: 16 October 2019
- Personalised care and support planning: a brief summary guide. NHS England. Date published: 29 August, 2023
- Palliative and end of life care: Statutory guidance for integrated care boards (ICBs). NHS England. Document first published:20 July 2022
- NHS Wales. Resources for health and care professionals. Advance and Future Care Plans
- A Palliative and End of Life Care Strategy for Adults in Jersey 2023 -2026. Government of Jersey. Published October 2023.

NACEL 2024 evidence

- **18%** of case notes had evidence that the person had participated in personalised care and support planning conversations prior to admission.
- **26%** of case notes had personalised care and support planning conversations during the admission but **56%** of case notes had no conversation recorded.
- **50%** of bereaved people said the person did not have an advance care plan in place before they died.
- Of the people expected to die during the hospital admission, **84%** had an individualised plan of care addressing their needs at the end of life.

Recommendation 4: Equitable care being delivered for all dying people

Recommendation:

Integrated care boards, health boards and commissioners should ensure that high quality end of life care is equitable and tailored to the needs of the local population by recognising and actively addressing current inequities across the local system. For example:

- Having a comprehensive understanding of the population living in the local area including the palliative care and end of life care needs of those with intersectional disadvantage e.g. from a local needs analysis, and/or through the use of existing data such as Fingertips
- Understanding the provision of hospital services that can support the local population's end of life care needs e.g. services to support an urgent release of the body
- Identifying gaps in provision and implement action plans to an agreed timescale
- Publishing strategic plans for the delivery of equitable palliative care and end of life care for all dying people

National recommendation responsibility:

Integrated care boards, health boards and commissioners

Guidance available

- Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. National Palliative and End of Life Care Partnership. May 2021
- End of life care for adults: service delivery. NICE guideline [NG142]1.2 Assessing holistic needs. Published: 16 October 2019
- Palliative and end of life care: Statutory guidance for integrated care boards (ICBs). NHS England. Document first published: 20 July 2022

NACEL 2024 evidence

- **14%** of case notes had unknown/not stated ethnicity of the patient recorded
- The overall rating of care for patients of Asian (**64%**), Black (**64%**), Mixed (**64%**), Other Minority Ethnic Groups (**58%**) and Unknown ethnicity (**59%**) were less likely to be recorded as excellent or good by bereaved people, compared to patients of White ethnicity (**76%**) (p<0.01).
- The bereavement survey feedback showed that hospital staff were least likely to communicate sensitively with those important to the dying person, when the dying person was of Asian ethnicity (**69%),** Undisclosed ethnicity (**61%**) or Other Minority Ethnic Groups (**56%**), compared to the national average of **83%** (p<0.01).
- Bereaved respondents were less likely to report that staff behaved with compassion and care where the patient was of Asian (**66%**), Black (**71%**), Mixed (**67%**), Other Minority Ethnic Groups (**63%)** and Undisclosed ethnicity (**58%**) than people of White ethnicity (**83%**) (p<0.01).
- **79%** of staff either strongly agreed or agreed that they are confident to respond to spiritual, emotional and cultural needs of the dying person.
- **64%** of clinical records had evidence of the patient's spiritual/religious/cultural needs being assessed, or where this was not possible a reason was recorded.
- **41%** of clinical records had evidence of those important to the person's spiritual/religious/cultural needs being assessed, or where this was not possible a reason was recorded.

- The proportion of bereaved people that strongly agreed or agreed that they were given enough spiritual/religious/cultural support was **46%**, where this support was required. Although ‘Not applicable’ responses have been removed, it is important to note that **42%** of total respondents for this metric selected ‘Not applicable’, suggesting that just under half of all respondents felt that spiritual, religious or cultural support was not required.
- **2%** of case notes had evidence that there was urgent release of the body (In **16%** of cases, it was unknown if there had been a request).
- **33%** of hospital/sites had an end of life care volunteer programme.

Recommendation 5: Training and support

Recommendation:

Integrated care boards, health boards and commissioners should consider system level initiatives aimed at increasing the uptake and quality of end of life care training. For example:

- Setting standards and establishing guidance, reflective of the local population need, for palliative care and end of life care training
- NACEL data highlights that training should include, but is not limited to, recognition of dying, pain management, discussions about drinking at the end of life and hydration, and assessment of spiritual, religious and cultural needs
- Seeking annual assurance from providers regarding numbers of staff who are undertaking training e.g. e-ELCA
- Developing strategic plans for staff training in palliative care and end of life care to support the delivery of end of life care

National recommendation responsibility:

Integrated care boards, health boards and commissioners

Guidance available

- Care of dying adults in the last days of life. NICE guideline [NG31]. Published: 16 December 2015
- Care of dying adults in the last days of life. NICE Quality standard [QS144].Published: 02 March 2017
- End of life care for adults. NICE Quality standard [QS13]. Published: 28 November 2011
- One Chance To Get It Right. Improving people’s experience of care in the last few days and hours of life. Leadership Alliance for the Care of Dying People. Published: June 2014 .

NACEL 2024 evidence

- **66%** hospital/sites with end of life care training included in induction programme during 23/24
- **51%** hospital/sites with end of life care training included in mandatory/priority training during 23/24
- **75%** hospital/sites with end of life care training included in communication skills training during 23/24

- **96%** hospital/sites offered some other form of end of life care training during 23/24
- **27**% of staff respondents strongly disagreed or disagreed that they had completed training specific to end of life care within the last 3 years
- **6%** of staff respondents either strongly disagreed or disagreed that they are confident in assessing and managing pain and physical symptoms at the end of life
- **12%** of bereaved respondents strongly disagreed or disagreed the person was given enough pain relief
- **14%** of bereaved respondents strongly disagreed or disagreed the person had enough relief of symptoms other than pain (such as nausea, breathlessness or restlessness)